Family History as a Screening Tool for Public Health and Preventive Medicine

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ACCE Course – Sept 27, 2004

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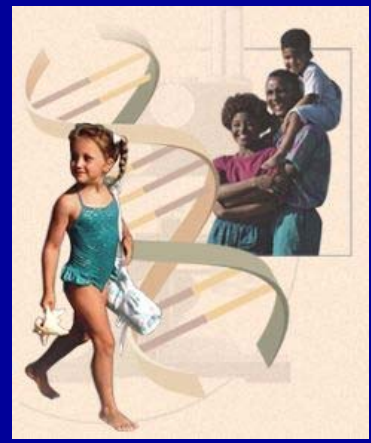
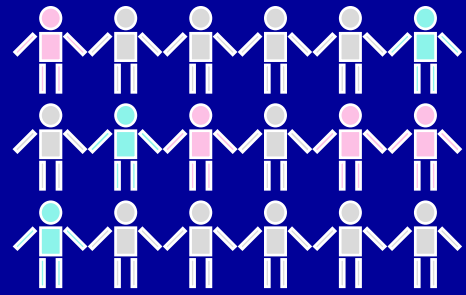
How can we use family history screening to...



- assess risk for common chronic diseases
- influence early detection and screening uptake
- target and prioritize prevention strategies

Why focus on family history screening?



- Current prevention strategies could be more effective
- Family history is risk factor for many common diseases
- Family history is underutilized in preventive medicine
- Need new tools for collecting, interpreting and acting

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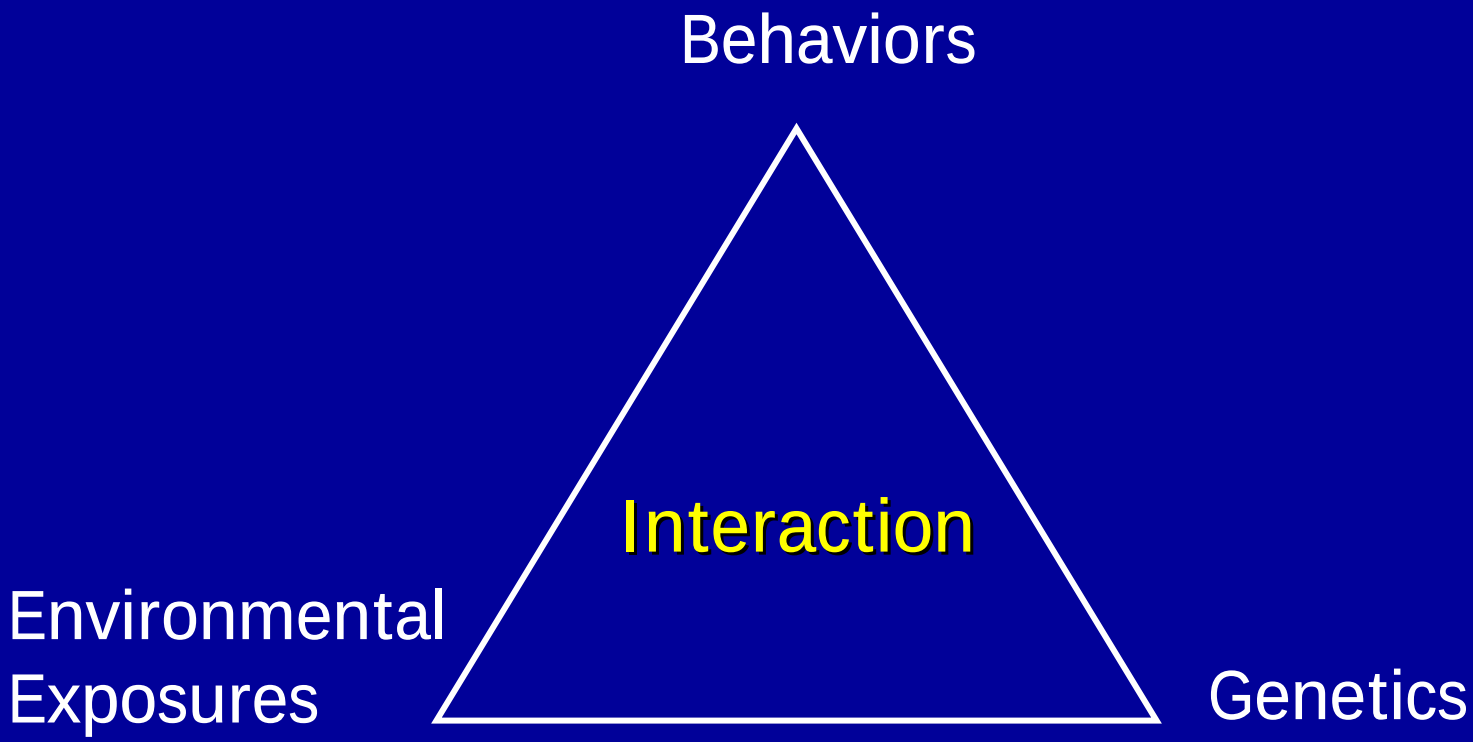
Current prevention strategies could be more effective

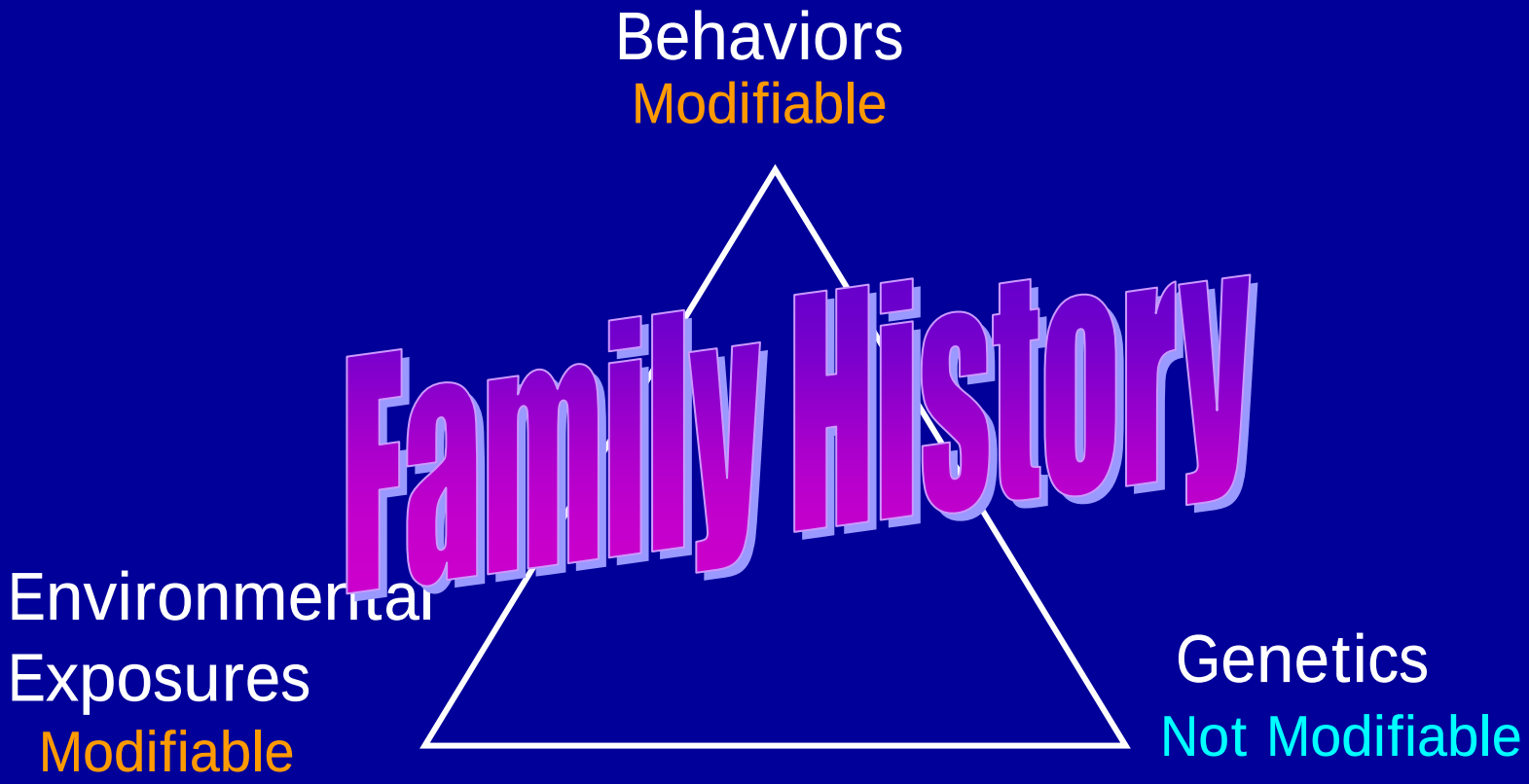
- 23% still smoke
- Only 25% engage in recommended physical activity
- Only 23% consume 5+ fruits & vegetables per day
- 2/3 overweight; 30% obese
- 48% eligibles screened for colon cancer

Causes of chronic disease



MT Scheuner, 2003

What is family history?



MT Scheuner, 2003

Family history is a risk factor for many common diseases

	Relative Risk
Heart disease	2.0 – 5.4
Breast cancer	2.1 – 3.9
Colorectal cancer	1.7 – 4.9
Prostate cancer	3.2 – 11.0
Melanoma	2.7 – 4.3
Type II diabetes	2.4 – 4.0
Osteoporosis	2.0 – 2.4
Asthma	3.0 – 7.0

Am J Prev Med - February 2003

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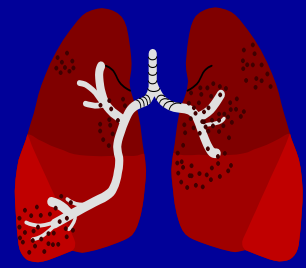
Usefulness of Cardiovascular Family History Data for Population-Based Preventive Medicine and Medical Research (The Health Family Tree Study and the NHLBI Family Heart Study)

Roger R. Williams, MD*, Steven C. Hunt, PhD, Gerardo Heiss, MD, PhD, Michael A. Province, PhD, Jeannette T. Bensen, MS, Millicent Higgins, MD, Robert M. Chamberlain, PhD, Joan Ware, MSPH, and Paul N. Hopkins, MD, MSPH

Detailed medical family history data have been proposed to be effective in identifying high-risk families for targeted intervention. With use of a validated and standardized quantitative family risk score (FRS), the degree of familial aggregation of coronary heart disease (CHD), stroke, hypertension, and diabetes was obtained from 122,155 Utah families and 6,578 Texas families in the large, population-based Health Family Tree Study, and 1,442 families in the NHLBI Family Heart Study in Massachusetts, Minnesota, North Carolina, and Utah. Utah families with a positive family history of CHD (FRS $\geq$0.5) represented only 14% of the general population but accounted for 72% of persons with early CHD (men before age 55 years, women before age 65 years) and 48% of CHD at all ages. For strokes, 11% of families with FRS $\geq$0.5 accounted for 86% of early strokes (<75 years) and 68% of all strokes. Analyses of >5,000 families sampled each year in Utah for 14 years demonstrated a gradual decrease in the frequency of a strong positive family history of CHD (−26%/decade) and stroke (−15%/decade) that paralleled a decrease in incidence rates ($r = 0.86$, $p < 0.001$ for CHD; $r = 0.66$, $p < 0.01$ for stroke). Because of the collaboration of schools, health departments, and medical schools, the Health Family Tree Study proved to be a highly cost-efficient method for identifying 17,064 CHD-prone families and 13,106 stroke-prone families (at a cost of about $27 per high-risk family) in whom well-established preventive measures can be encouraged. We conclude that most early cardiovascular events in a population occur in families with a positive family history of cardiovascular disease. Family history collection is a validated and relatively inexpensive tool for family-based preventive medicine and medical research.

(Am J Cardiol 2001;87:129–135)

The Health Family Tree Study
Utah, 1983-1996



- Students completed forms in health classes
- Family history data collected on siblings, parents, aunts & uncles, grandparents
- Family history score calculated for each disease
- Report mailed to each family
- Public health nurses visited high risk families

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Data Collection Form

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BROTHER OR SISTER OF PERSON 2

Relative's First Name _____

Blood relative of person#2 ☐ Yes ☐ No ☐ Male ☐ Female
In-state resident? ☐ Yes ☐ No
Living? ☐ Yes ☐ No

Year of birth_____ Age (now or at death)_____

Causes of death_____

_____

Number of natural children of this person_____

Has he/she ever been told BY A DOCTOR that he/she suffers from any of the following health problems?

YES	NO	NOT SURE	AGE AT FIRST DIAGNOSIS	Condition
☐	☐	☐	_____	Heart attack (hospitalized)
☐	☐	☐	_____	Angina pectoris (on medication)
☐	☐	☐	_____	Coronary bypass surgery
☐	☐	☐	_____	Rheumatic or other heart disease
☐	☐	☐	_____	Stroke
☐	☐	☐	_____	Breast cancer
☐	☐	☐	_____	Lung cancer
☐	☐	☐	_____	Colon cancer
☐	☐	☐	_____	Other cancer (excluding skin cancer) Type:_____
☐	☐	☐	_____	High blood pressure (on medication)
☐	☐	☐	_____	High blood cholesterol
☐	☐	☐	_____	Diabetes

CIGARETTE SMOKING

☐ Smoker: Has smoked cigarettes regularly for at least 1 year
☐ Ex-smoker: Stopped for at least 1 year after smoking regularly
☐ Non-smoker: Never smoked cigarettes regularly
☐ Not Sure

IF SMOKER OR EX-SMOKER mark average amount smoked

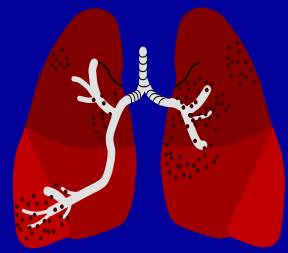
☐ Less than 1 pack a day
☐ About 1 pack a day
☐ More than 1 pack a day

USUAL WEIGHT

☐ Slender or average
☐ 10-49 lbs. overweight
☐ 50-99 lbs. overweight
☐ Over 100 lbs. overweight
☐ Not Sure

ALCOHOLIC BEVERAGES (beer, wine, liquor)? ☐ Regularly ☐ Never ☐ Sometimes ☐ Formerly ☐ Not Sure

Vigorous ROUTINE EXERCISE at least 3 times per week?
☐ Yes ☐ No ☐ Not Sure



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Family History of CHD in the Health Family Tree Study

FHx Score	% Families	% Early CHD	% All CHD
≥0.5 (positive)	14	72.1	48.4
≥1.0 (str pos)	3.2	34.7	17.6
≥2.0 (v str pos)	1.0	16.8	6.3

Includes data from 122,155 families; 16,602 early CHD cases; 54,182 cases of CHD at any age

Williams, et al. *Am J Cardiol* 2001; 87:129-135

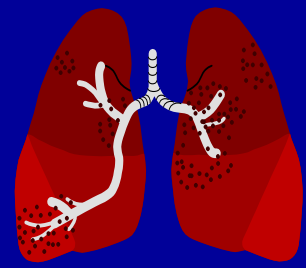
Family History of Stroke in the Health Family Tree Study

FHx Score	% Families	% Early Stroke	% All Stroke
≥0.5 (positive)	11	86	68
≥1.0 (str pos)	1.4	22	16
≥2.0 (v str pos)	1.0	19	12

Includes data from 122,155 families; 4,600 early stroke cases; 22,425 cases of stroke at any age

Williams, *Am J Cardiol* 2001;87:129

The Health Family Tree Study
Utah, 1983-1996

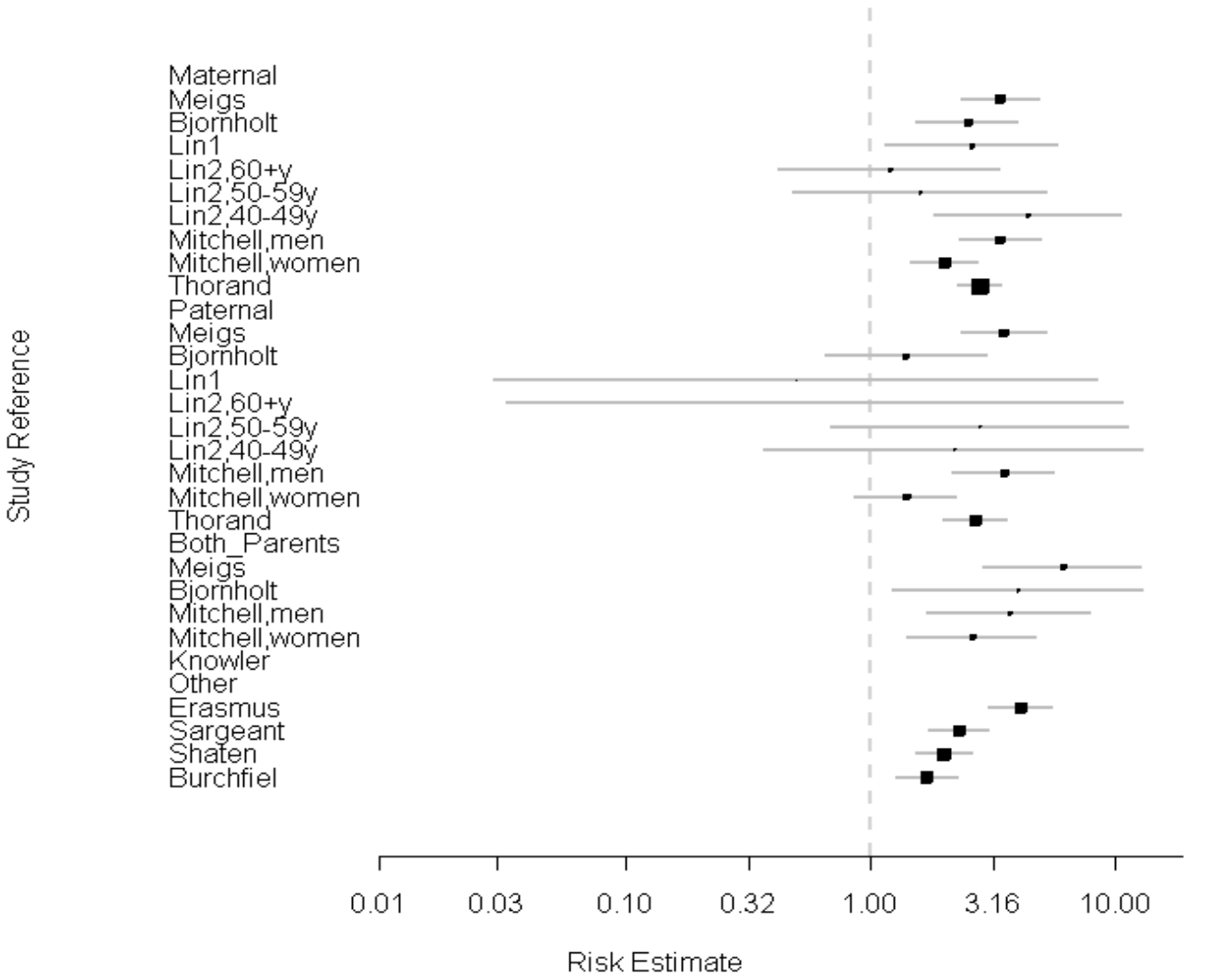


Results

- Small subgroup of families have greater burden of disease
- These families can be identified
- May benefit from targeted prevention measures

Risk Estimates for FHx of Diabetes

Harrison TA, et al. Am J Prev Med 2003;24:152-9



- Consistent positive association
- Relative risks range from 1.5 to 6
- Familial risk factors

Family History Collection by PCPs

- Family history collected at about 50% of new visits and 22% of established visits

- Average duration of visit, 10 minutes; average duration of family history discussion, 2.5 minutes

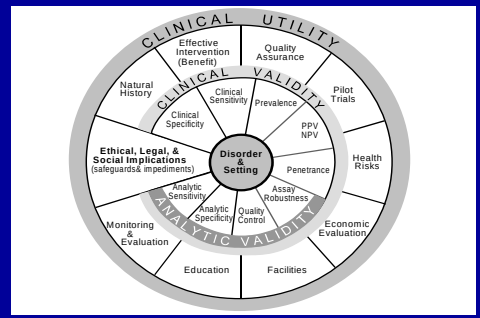
  Acheson et al., 2000

- Only 29% of PCPs feel prepared to take family history and draw pedigrees

  Suchard et al., 1999

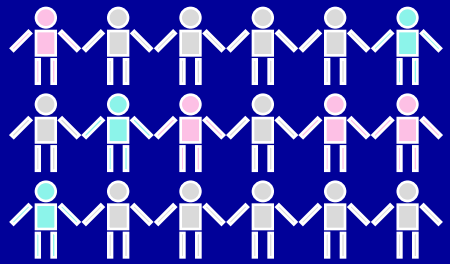
Family History Public Health Initiative

Evaluate the use of family history for assessing risk of common diseases and influencing early detection and prevention strategies



Components

- Assessment of existing strategies
- Tool development
- Research and evaluation
- Public awareness and provider education



Assessment of existing strategies

- Can family history be used as a tool for public health and preventive medicine?

  Genet in Med 2002

- Expert panel – May 2002

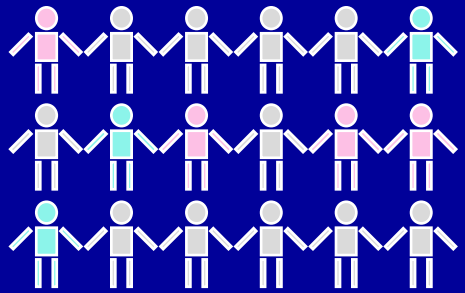
  Am J Prev Med Feb 2003

- Family history work group

- Research agenda and criteria for disease selection

Selection of diseases for a public health tool

- Substantial public health burden
- Well defined case definition
- High awareness of disease status among relatives
- Accurately reported by relatives
- Family history is an established risk factor
- Prevalence of family history can be estimated in the popu
- Effective interventions for primary and secondary prevention
- Different recommendations for familial risk groups



Tool development

- Reviewed existing family history tools
- Selected diseases based on criteria
- Established design principles
- Developed process for familial risk assessment and personalized prevention messages

Family history tool – design principles

Family History Tool

- Self-administered
- Easily applied and adaptable to different settings
- Simple but collects enough information to stratify risk
- Tied to algorithms that interpret risk
- Useful in combination with other risk factors
- Useful for targeting interventions
- Tied to resources for risk-appropriate intervention and referral

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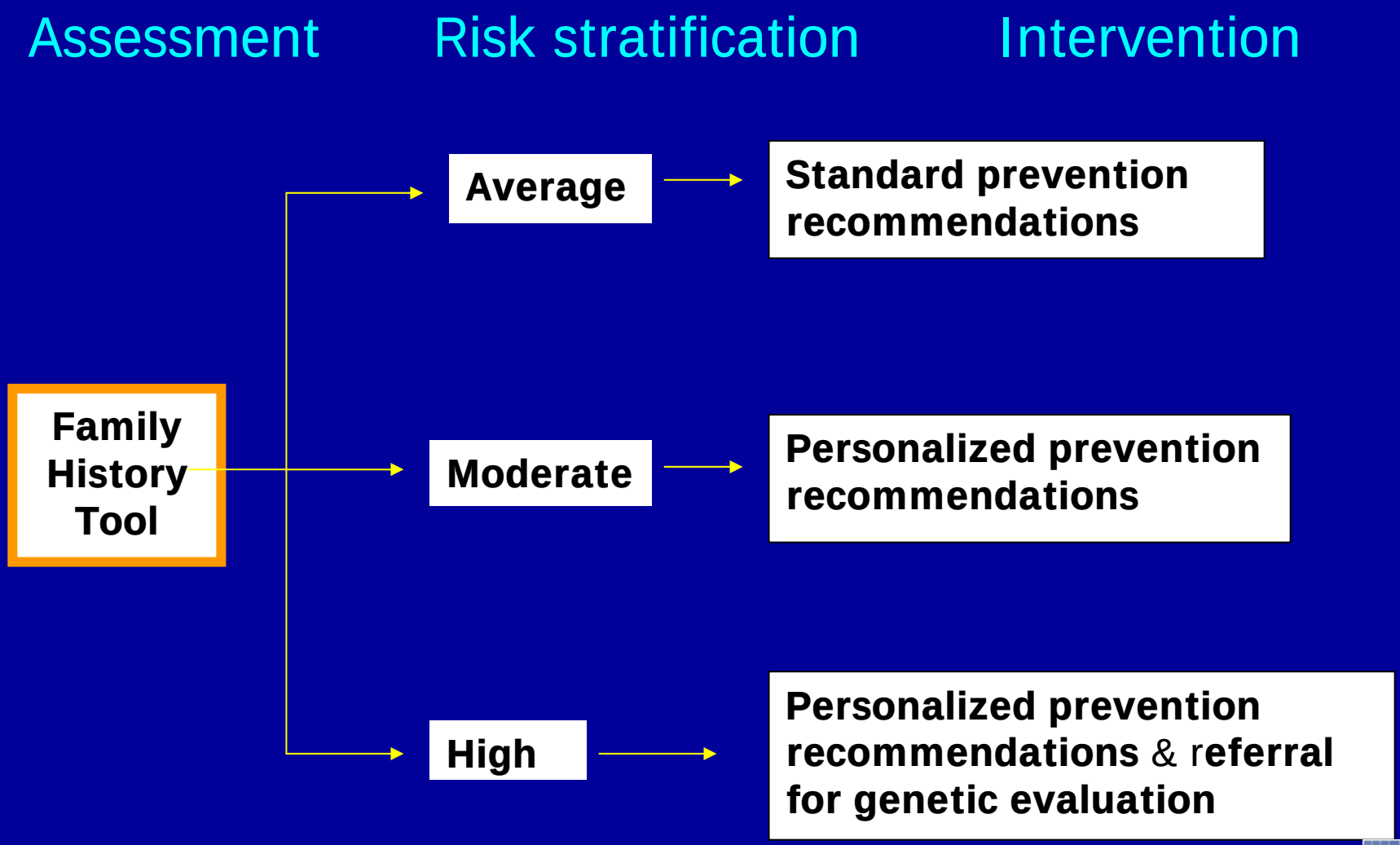
Family history tool – design concept



Algorithms for classifying risk

Family History Tool

Scheuner M et al.
Am J Med Genet
1997;71:315-324.

Table 2
Suggested guidelines for risk stratification based on family history

High risk

1. Premature disease in a 1st-degree relative
2. Premature disease in a 2nd-degree relative (coronary artery disease only)
3. Two affected 1st-degree relatives
4. One 1st-degree relative with late or unknown disease onset and an affected 2nd-degree relative with premature disease from the same lineage
5. Two 2nd-degree maternal or paternal relatives with at least one having premature onset of disease
6. Three or more affected maternal or paternal relatives
7. Presence of a "moderate risk" family history on both sides of the pedigree

Moderate risk

1. One 1st-degree relative with late or unknown onset of disease
2. Two 2nd-degree relatives from the same lineage with late or unknown disease onset

Average risk

1. No affected relatives
2. Only one affected 2nd-degree relative from one or both sides of the pedigree
3. No known family history
4. Adopted person with unknown family history

From Scheuner et al.[9]

Resource Manual

Family History Tool

Chapter for each disease

- Assessment of additional risk factors
- Explanation of risk levels and potential genetic conditions underlying high risk e.g., HNPCC
- Recommended interventions for each level of risk (if available)
- Additional resources for providers and patients

Address: http://www.familyhealthware.org go

Favorites History Search Scrapbook Page Holder

Family Healthware

Using Family History to Promote Health

Welcome to Family Healthware

Family Healthware will create a personalized prevention plan based on health information about yourself and your family members. The plan assesses your risk for six diseases, and recommends screening tests and lifestyle changes with the goal of improving your health.

Learn more about family history and its role in health and disease prevention

- Why is family history important to health?
- Why is knowing family history important?
- What aspects of family history affect disease risk?
- What if there is no family history of disease?

Learn more about using Family Healthware

New Users

Begin your Family Healthware assessment today...

Create My Profile ▸

Returning User Login

Username:

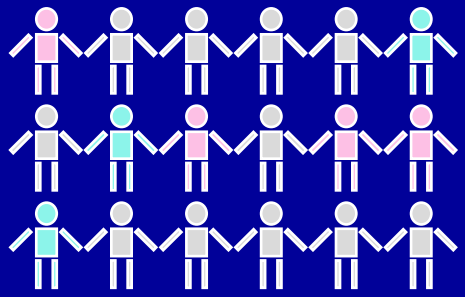
Password:

Go ▸

Forgot your username or password?

All decisions regarding your medical care must be made in consultation with a healthcare professional. Family Healthware is not designed to replace individualized medical advice and discussions with a healthcare professional.

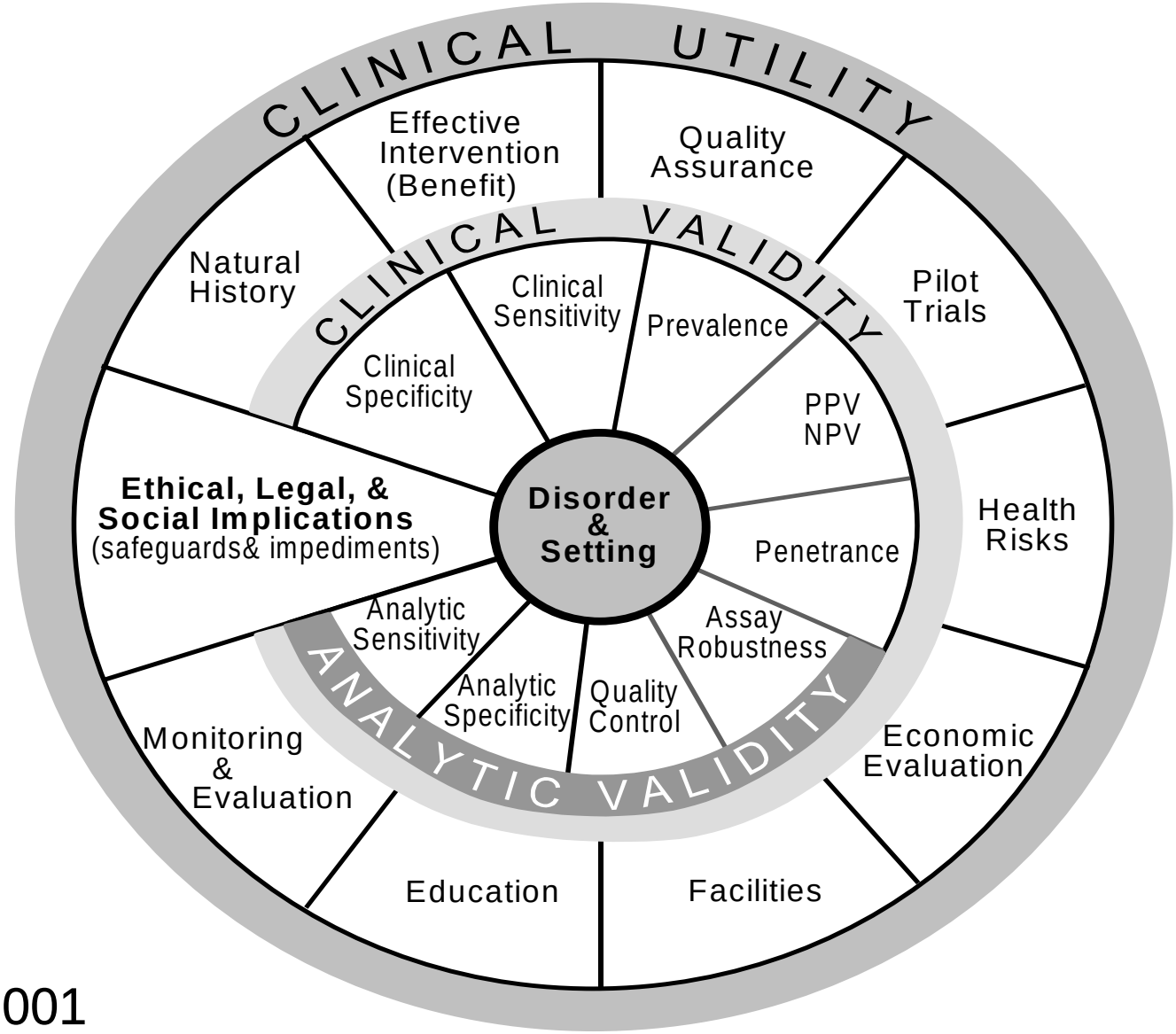
We recognize the importance of protecting privacy of information collected with Family Healthware.
View privacy policy.



Research and Evaluation

- Cognitive testing – focus groups and one-on-one
- Pilot studies – different population groups
- Evaluation study – primary care clinics
- Validity and utility studies with existing data

ACCE Evaluation framework



FBR, 2001

Public health awareness & provider education

- Public health messages & communication strategies
- Provider education programs
- Collaborations
  - Surgeon General's National Family History Day
  - Professional organizations
  - Health Departments

Acknowledgements

CDC Family History Team

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Family History Work Group